Little Court

Stakeholder Engagement

January 2021

In December 2020 I was engaged by Phil Jordan and Stuart Harris, Directors of Central and Regional Estates Limited (CARE) to undertake a piece of consultancy involving engagement of key stakeholders in relation to the proposed development of a dementia care village at 'Little Court' in Little Wratting, near Haverhill in Suffolk.

This is a summary of the feedback I gathered during January 2021. Prior to this work I was informed of prior engagement work by the directors of CARE, and this was evident from some stakeholders I spoke with who were aware of the project. The target group to seek views from were health and social care professionals, commissioners, the voluntary sector, and local community organisations and groups.

Potentially engagement with these people was limited due to the current COVID-19 pandemic being their priority, however most people contacted so far have been responsive and genuinely interested in this project which is encouraging and possibly due to the innovative nature of the proposal, focus on improving quality of life for people with dementia and the opportunity to influence the development at an early stage.

Range of stakeholders

During January 2021 I engaged with over 25 health and social care professionals and people with an interest in dementia care provision in Suffolk. These included commissioners of services, those responsible for delivering dementia strategy and transformation work, service providers, health and social care practitioners and local groups working directly with people with dementia.

Meetings were virtual via Microsoft Teams. I shared slides and information to take people through detail on design, the proposed model of care based on Hogeweyk in the Netherlands, as well as ideas discussed with CARE to work collaboratively to offer additional support and value to the local community. To aid the discussion the following standard questions were asked:

- Have you heard of Hogeweyk or dementia villages, if so your view on the concept?
- What are your initial thoughts about the proposed Little Court development?
- Is there a need for specialist dementia care facilities in West Suffolk?
- What do you think about the care model and concept? i.e., small group living, lifestyle types, living life as normal.
- Will this fill a general and/or niche need?
- How will the proposed development alleviate pressure on NHS and other care providers?
- What do you think of the proposed cost of the care?
- What do you think about the opportunities Little Court could offer to people living with dementia in the surrounding community?
- How can CARE continue to engage with you?

Model and concept

Some stakeholders had heard about Hogeweyk and been interested in its unique approach although no one seemed to understand it in any detail. It is fair to say the dementia care village in the UK is a new concept. One or two people only questioned if the creation of a dementia village is in opposition to the general strategic focus to keep people in their own homes and communities. It was important to explain that the CARE model is for people with 'severe' dementia who require 24-hour supervision and care and would otherwise need a care home environment. Little Court itself would be a community where residents stay to the end of their lives. It was also acknowledged by other stakeholders that at a progressed stage of dementia the quality of life you have within your own home can be limited due to isolation and inability to access your local community and potentially unsuitable accommodation.

Julia Parish who leads Suffolk County Council Adult and Community Services' Specialist Dementia Team, is familiar with the Hogeweyk model and really likes it. She thinks the freedom, it potentially offers is fantastic and sees how it can have a positive impact on quality of life for people with dementia, particularly in minimising behavioural, psychological symptoms of dementia (BPSD). She feels the risk assessments that are necessary for people in current care settings are so very restrictive and for some can lead to a 'caged tiger' mentality. Accessing the outdoors and local facilities freely is part of everyday life we take for granted but this is not an option for most people living with advanced dementia in the UK whether they live in a care home or their own home.

I spoke to the team of dementia navigators who work for jointly commissioned service 'Dementia Together Suffolk'. They have supported a small group of younger people living with dementia in Suffolk and reported that some of these service users had attended a presentation by CARE. All were very positive about the proposals for Little Court and opportunities it could offer to enable them to continue to live active lives. There has been a long-established gap in Suffolk for appropriate accommodation-based care for early onset dementia in younger people. This is a specialist and niche area that could be accommodated within Little Court that commissioners I spoke to would be interested in.

The key concepts of small group living, living with people who share your values and living life as normal were considered by all stakeholders to be very positive, although with comment that there should be flexibility allowed for people to be able to 'move houses' if the 'lifestyle' selection they and their families had chosen was not working for them.

Need for this type of development.

All stakeholders I spoke with are aware of the national and local public health data forecasting the significant increase in people developing dementia over the next 20 years. It is accepted that more care services will be needed. What they are actively exploring are the solutions to a ticking time bomb and recognising that they need to consider innovative new models of care. When I spoke to a group of Suffolk County Council Adult and Community Services (ACS) staff (commissioner, social workers, and housing and contracts team members), all were unanimous in there being a need for this type of specialist development in Haverhill. The idea of living at Little Court and not being forced to move because of a change in the level of support one requires was welcomed by this group as it differs positively from the tiered system that exists now. They are also interested in how assistive technology and digital care innovations could work at Little Court and the ACS digital lead is keen to explore this with Directors of CARE.

The financial model is based on private funders. Most stakeholders said they would like to see Little Court available for all local people who might need it rather than a two-tier system. Directors of CARE are open to working with Suffolk County Council to explore possibilities of contracting some provision and the opportunity is open to discuss things further with the contracting team.

The Dementia Village concept, design and facilities present opportunities to offer support and services beyond registered residential and nursing care, enabling people living locally with dementia and their carers to benefit from these. The Directors of CARE are keen to explore ideas and collaborate with others to deliver these.

During meetings with Gail Cardy of West Suffolk Clinical Commissioning Group and Rachel Combes of Suffolk County Council who have responsibilities for commissioning and transformation of dementia services for their respective organisations, both were very interested in how Little Court could link with and be of value to local people living with dementia and their family carers.

In 2015 The Suffolk Health and Wellbeing board signed up to a vision for Dementia Friendly Suffolk. Whilst progress has been made with Dementia Action Alliances (DAAs) helping to raise awareness about dementia, the enabling of communities to become dementia friendly has been slow and both Gail and Rachel would be very keen to see Little Court act as a demonstrator site providing education and advice to others, including local DAAs, local projects and groups, and community leaders to enable the growth of 'Dementia Friendly Suffolk'.

The need for respite care was flagged by several stakeholders; more specifically a shortage of available beds for respite when families needed it and a shortage of day care options. A stakeholder mentioned a big need for somewhere families can drop off and safely leave their relative in the knowledge they are safe and engaged in enjoyable and therapeutic activities. There is the opportunity for local organisations to work with Little Court to provide such day support options through leasing space and running clubs on site or by supporting their service users to attend the hobby clubs operated on site at Little Court.

I spoke with Nathalie Guilder who is a key domiciliary care provider in Haverhill. She was very clear about the need for a development of this type in the area, she is aware that often carers cannot access respite beds locally and there is a big need for this. Nathalie was involved in initiating Haverhill Dementia Action Alliance and describes the town as very 'community spirited'. She also operates a day service utilising several volunteers, there being many older retired people who are keen to give something back. She feels this is an untapped area. She is very keen to explore opportunities to work with CARE should the project proceed.

Whilst there has been lots of positive publicity and articles about Hogeweyk, as well as qualitative evidence, there appears to be no research or identification of clinical outcomes and this appears to be the case in general for dementia care villages. I spoke with Andreea Tocca, Research Development Manager at The University of Suffolk (UoS). Andreea and her team have been engaged in various health and dementia related projects. She is aware of Hogeweyk's innovative approach. As this is such a new concept for the UK, Andreea feels it would attract interest and it will be important to gather evidence regarding the model of care. UoS and The Integrated Academy of Care would be interested in evaluation and research working with CARE.

Relieving pressure on NHS

Sarah Hedges, Integrated Transformation Lead at Suffolk Community Services was encouraged to hear about this potential development as she feels Haverhill is an area of Suffolk which often gets

overlooked despite there being a need. She is currently involved in work which looks at how we enhance community services, and this could fit in well with that. A key driver is to keep people in their own surroundings and out of hospital and this presents an opportunity to work together to do that. There are local health priorities regarding management of frailty and falls which lead to a higher rate of hospital admission in the Haverhill Integrated Neighbourhood Team area; there is potential for the proposals to help reduce this.

Clinical Consultant Psychologist Rebecca Poz had read literature about Hogeweyk and noted they had reported a reduction of use of antipsychotic medication over time by 50% with people who have behavioural and psychological symptoms of Dementia (BPSD) and agrees that this is likely to be attributed to the freedom, lifestyle living and approach to engage in meaningful activity. Reductions in this type of prescribing and drug usage will save money and could reduce pressure on NHS services reducing input needed from services such as dementia intensive support teams. This was echoed by Julie Parish (see above), who also spoke about the need to improve the quality of the local care home provision that currently exists to meet the needs of those people who present with BPSD.

Other engagement

The Directors of CARE have spoken to some local GPs. Currently engagement is understandably limited given their current workloads. I have spoken to Lois Wreathall, Deputy Director of Primary Care West Suffolk Clinical Commissioning Group, who has all the information and will link with the GPs to seek further input.

CARE have had advice from The Care Quality Commission, and I have had contact with a local inspector who is interested by the Hogeweyk approach. Further discussion is planned.

I am awaiting further feedback from local people living with dementia and their carers via Dementia Together and other organisation members of The Suffolk and North East Essex Dementia Forum.

Further engagement is planned with Norfolk and Suffolk NHS Foundation Trust, Dementia Intensive Support team.

This engagement exercise is a work in progress and there are many potential stakeholders. Directors of CARE are keen to continue to explore opportunities to work collaboratively with health and social care commissioners as well as local groups and care provider organisations.

Jo Marshall

RMN, Health and Social Care Management Consultant

JO MARSHALL CONSULTING LTD Tel 07809570322 marshalljoanne33@gmail.com Company number 11034402